

An IFSP Story

This is the IFSP story of Latisa (“Tisa”) Richardson and her parents, Mae and James. Tisa is the Richardson’s first child. She was born 6 weeks prematurely and weighed 2 lbs. 14 oz. at birth. The first weeks of Tisa’s life were a scary and stressful time for Mae and James. Tisa had to be resuscitated at birth and stayed in the neonatal intensive care unit (NICU) for 7½ weeks. She was on a respirator for the first week and remained on oxygen throughout her stay in the NICU. She suffered a mild intraventricular hemorrhage shortly after she was born and was also diagnosed as having severe bronchiopulmonary dysplasia.

At the time of her discharge from the hospital, Tisa weighed about 4½ pounds and still required supplemental oxygen. Mae learned how to administer oxygen at home and the family rented equipment for home use.

When Tisa was ready to go home, Linda Carter, the Community Transition Coordinator covering the NICU, called to inform the Children’s Developmental Services Agency (CDSA) in her region that Tisa was being discharged, as she had made a referral to the CDSA earlier. She explained to Mae and James that Tisa could potentially be eligible for early intervention services through the Infant Toddler Program because she had an “established condition” - the neonatal complication of bronchiopulmonary dysplasia requiring supplemental oxygen at discharge from the NICU. James and Mae decided that they did not want to receive early intervention services at that time. They felt that Tisa was improving and were confident they could take care of her needs. “We can’t wait for it to be just us at home with her,” Mae told Linda. “Maybe we can finally be a normal family.” When a staff member from the CDSA called them, they declined ITP services.

The first year of Tisa’s life brought additional challenges. Although her supplemental oxygen was tapered off and discontinued within 6 weeks, Tisa had chronic respiratory infections. She was hospitalized twice for pneumonia and once for what appeared to be an asthma attack. Her respiratory problems tapered off as she approached her first birthday, but new worries cropped up. James and Mae were worried that Tisa wasn’t gaining much weight or getting close to walking. She liked to be supported in a standing position, but her legs seemed tight and she didn’t try to step. Mealtimes were fussy times and there were very few foods that Tisa seemed to enjoy.

Money was tight, too. James is a mechanic at a small garage. He earns enough to feed the family and make payments on their mobile home, but there is not much left over. Mae used to work in a drugstore and planned to go back after Tisa was born, but she didn’t want to leave the baby in child care because Tisa had been sick so much. Fortunately, James has medical insurance that covers most of Tisa’s medical expenses, but even the unpaid balance imposed a financial strain. They tried to pay a little bit on the medical bills each month.

When she was about 13 months old, Tisa had her 1-year well child visit with her pediatrician, Dr. Tim Sanders. Mae shared her worries about Tisa with Dr. Sanders. Based on the medical examination and developmental screening he performed, Dr. Sanders told Mae that he was concerned, too. Tisa was “off the bottom of the weight chart” for her height, which was

only in the 5th percentile. She appeared to be delayed in her development more than would be expected due to her prematurity alone. Dr. Sanders suggested that Tisa might benefit from early intervention services, and this time Mae agreed. She gave permission for Dr. Sanders to share her contact information and Tisa's medical information with the CDSA.

A few days after her visit to Dr. Sanders, Mae received a call from Grace Williams, an Early Intervention Service Coordinator from the CDSA. Grace explained that she would be their service coordinator and that she would like to schedule a visit to get to know the family better.

"What does that mean, 'service coordinator?'" Mae asked. I told Dr. Sanders I wanted to get some help for Tisa, but what do you do, exactly?"

"First, it's my job to learn as much as I can about Tisa and what you want for her," Grace explained. "Then we can work together to figure out the best ways to help her grow and develop, and what kind of supports she might need. Sometimes there are several different people involved, and it's my job to help everyone work together. If you are not sure who to call, you can always call me."

"Well, that's good," said Mae. "I'm not all that crazy about a lot of people coming in and out of my house. If it's just you, it will be easier."

"There might be some other people, but only if you want them," Grace reassured her. "Maybe I could start by visiting you sometime this week. Is there a time that would be good for you?"

Mae and James decided they both wanted to be at home for Grace's first visit, even though it was hard for James to take off work. They scheduled the visit after breakfast, so James could just go in a little late and Tisa would hopefully be dressed and ready to play. Grace arrived right on time and, after greeting all three of them, asked where they would like to meet. Mae suggested the living room, so Tisa could play on the floor with her toys.

Grace began by explaining again that, as their service coordinator, it was her job to find out what they want for Tisa and what concerns they have about her development. "We'll do some more assessments of Tisa's development, to add to what Dr. Sanders did and find out for sure whether Tisa is eligible for the Infant-Toddler Program. Then we can decide together what to do about the concerns you have. Today I can tell you a little more about the program and what it involves. You can tell me more about Tisa and anything about your family that you want me to know. Then, if you want to participate in the program, there is some paperwork we can get started on. Does that sound OK?"

James explained that he couldn't stay all morning, and Mae said she had some errands she wanted to run before lunch. "It's OK, we don't have to do everything today," said Grace. "We can wrap things up whenever you need to and I can come back another day."

"I really just want to know what this is going to involve," said Mae.

Grace explained briefly that the Infant-Toddler Program provides early intervention services for children ages birth to three with special needs, and their families. "This means that we will work with you to help Tisa grow and develop and learn as much as possible," she continued. "The way we do this is to write an IFSP, an Individualized Family Service Plan. You help us write the plan to make sure it covers what is important to you. The IFSP lays out how everyone who is involved will work with you and Tisa."

“Is there a charge for this?” asked James. We’ve got too many medical bills already.”

“There is no charge for developing an IFSP or for what I do to coordinate services,” answered Grace. “There is sliding fee scale for some services, and the medical expenses you already have would be taken into account. Some services can be billed to your health insurance if you want us to do that. I can tell you more after we decide what supports Tisa needs.”

“How much time does this take?” asked Mae.

“It usually takes several visits like this to decide what Tisa needs and what you want for her, and to write the IFSP,” explained Grace. We always try to work around your schedule. After that, it’s up to you. For example, I noticed from Dr. Sanders’ report that you are worried about Tisa’s stiff legs. If you decided you wanted her to have physical therapy, you could have someone come to your home, or other environments that are natural for Tisa, or you might want to learn to do the therapy yourself. Whatever you choose, you would decide how often to do it.”

“We want to do everything we can for Tisa,” emphasized Mae. “I’m just trying to figure out what’s involved.”

“I know it’s a little confusing at first,” Grace acknowledged. “Maybe it would be good for you to tell me a little more about Tisa. I think that will lead us toward some answers to your questions.”

At this point, Tisa, who had been playing with her favorite “Boo Bear” on the floor, moved toward Grace using an “army crawl” and grabbed the nearest leg of the coffee table, vocalizing loudly.

“That means she wants to play at the table,” said James.

“Is it OK if I put her up to the table?” asked Grace.

“Sure,” said Mae. “You have to steady her hips a little, but she loves to play up there.”

“Hi, Tisa,” said Grace, making eye contact with the child. “I’m going to help you stand at the table.” Tisa gave her a big smile, and Grace said, “Oh, I like that smile!” Tisa continued to coo and babble as she played with her toys at the table. At one point she said “Da!” as she gestured toward a toy that was out of reach. Grace said, “You want that little car,” and handed it to her.

Mae felt reassured to see how Tisa had taken to Grace. She thought that Grace seemed to know exactly what to do with Tisa. “That’s how she always is with people,” said Mae proudly. “I mean, she likes us best, but she’ll play with anybody who’s nice to her.”

“Tell me more,” said Grace. What else does she like to do?”

“Well, like you saw, she really just likes to play on the floor with her toys. That bear is her favorite. It has to go with us everywhere. She’ll say “buh-buh” when she wants him, and you’d better find him quick. She likes to ride in the car, but she doesn’t really like to sit in the car seat when we stop. Oh, and she loves her naps. She’ll fall asleep anywhere if she’s tired. She pulls herself across the floor and follows me from room to room making her little noises. We talk to each other all day. She likes her bath, too.” It was clear that Mae enjoyed telling Grace the good things about Tisa. James nodded his agreement with Mae’s account.

“It sounds like she’s fun to be with a lot of the time,” said Grace. “I know you’re worried about some things, too. Can you tell me about those?”

“Well, mainly that she’s so skinny,” said Mae with a frown. We keep trying to fatten her up, but she doesn’t like to eat. She’s real fussy at mealtime. It might be because she’s been sick so much. When she was little, her nose was sometimes so stuffed up that she couldn’t drink her bottle. It was really hard. She’s better now, but there are not many foods she will eat.

“So it sounds like it’s still hard to feed her,” said Grace. “Is there anything that seems to help?”

“Give her mashed potatoes and applesauce,” said James.

“Yeah, those are her favorites,” agrees Mae. “Sometimes crackers, cookies, or baby food fruit. Cereal for breakfast if she’s really hungry. She still has a bottle during the night and in the morning but she drinks apple juice after that.”

“What about other times of day?” asked Grace. “How do those usually go?”

“Getting her up is hard,” replied Mae. “She doesn’t always go back to sleep after her bottle during the night, and then she’s tired in the morning. But once she’s awake, she’s pretty cheerful. She likes getting dressed and she likes her pretty clothes. But those tight pants and leggings are hard to get on her because her legs are so stiff.”

“I can see she’s cheerful by this time of day,” commented Grace, who was still helping Tisa stand and play at the coffee table. “What about lunch and naptime?”

“She actually takes several naps,” explained Mae. “She’ll probably get sleepy in a little while and want to be up here on the couch by me. We just let her fall asleep when she gets tired. She has lunch whenever she’s awake, so it’s not always at the same time.”

“We all eat supper in here so we can watch the news,” James added. “If she’s sleeping, we go ahead and eat and then feed her when she wakes up. She likes to sit in my lap to eat.”

“Yeah, sometimes she’ll eat a little more then,” Mae agreed. “But she eats in her Exer-Saucer if we’re eating. Or plays with her food, mostly.”

“So it sounds like you are worried about how little she eats, and we mentioned her legs being tight,” Grace summarized. “Is there anything else you’re concerned about right now?”

“About her legs,” replied James, “What I really want is for her to walk. She needs to get out more and seek the world like any other child would. Yeah, she follows us around the house, but when she’s outside she stays in one place. And she doesn’t have good balance. She likes the sandbox until she falls over in it, and then she cries. Same with the swing. She keeps sliding down or tipping over to one side.”

“Or in the grocery cart,” added Mae. “It makes it hard to shop when you have to hold her all the time, and she hates the stroller unless it’s moving.”

Grace noticed that Tisa had stopped playing with her toys on the table and started to whimper a little. “Are you ready to get down?” she asked. Tisa looked over at Mae and Grace lowered her gently to the floor. She crawled the short distance to the couch, pulled on Mae’s leg and looked up at her.

“Come on up, baby,” said Mae, lifting Tisa up and reaching for Boo Bear. Tisa snuggled against her mom with heavy eyes, Boo Bear clutched to her cheek.

“It looks like she falls asleep pretty easily,” Grace commented.

James rolled his eyes. “Well, yes and no,” he said. “Now she will. But at bedtime it’s another story. Like Mae said, she loves her bath and would stay there all night. She sits in one of those ring things that holds her up. But she’d rather stay up with us after that, especially if she had a late nap.”

“We tried just leaving her in her bed but she cries and cries,” added Mae. “So we usually watch TV until she falls asleep here on the couch with us and then we put her in bed. But sometimes that’s pretty late. Then during the night, after her bottle, she’s ready to play. We bring her in the bed with us so we don’t have to listen to her cry. But at least one of us doesn’t get much sleep for a while.”

“I think she’s got her days and nights mixed up,” said James. “Something’s got to give, because I can’t keep going to work tired.”

Grace tended to agree with James and resisted the urge to give advice about how to handle the problem, knowing that it was probably too soon in her relationship with the Richardsons and that she might not understand the situation fully. “That’s something we could put in the IFSP to work on if you want to,” she said.

James nodded. “Speaking of work,” he said, “I’ve stayed as long as I can right now. What happens next?”

Grace replied, “If you both still feel that you want to participate in the Infant-Toddler Program, I will give you this Parent Handbook for the program, and a description of your rights as a family. You can take a look at them and I can tell you more about the program, explain these rights and answer questions the next time we get together. Mae, if you have a little more time, we can start on some of the paperwork now and I can answer your questions even though James needs to leave. Then I’ll schedule another visit pretty soon so we can continue the process of finding out for sure if Tisa is eligible and getting her enrolled. We have 45 days to complete the IFSP if she is eligible, and if not I can help you to find other resources in the community to help with your concerns about Tisa.”

James nodded again and stood up. “I want to go ahead,” he said. He looked at Mae and she nodded. “But I can’t come to a lot of meetings,” he continued. “Mae is the one who takes care of Tisa most of the time.”

“That’s OK,” replied Grace. “I hope you will be involved as much as you want to be, but it’s up to the two of you how to handle all of this.”

After James left, Grace and Mae worked together to fill out some of the forms required for enrollment in the Infant-Toddler Program while Tisa napped. Mae appreciated how Grace explained the purpose of each form clearly and answered her questions. She felt she was not being rushed to sign anything that she did not understand. When she told Grace that James would need to help with the Financial Eligibility Application, Grace agreed to leave the form with her and made sure she understood what information would be needed. They scheduled another meeting for the next week at the same time of day.

Before she left, Grace showed Mae a form called *Welcome to My World!* Mae noticed that it wasn’t very long and didn’t look too hard to fill out. “I really enjoyed learning about Tisa today,” Grace said. “This form helps to make sure that we have covered the most important things you want me to know about Tisa and your family. It asks about what’s going well, what you are concerned about, and what happens during different parts of your day. We talked about a lot of the things that you would probably put on this form today. I can leave it with you to fill out, or I can write down what I remember and we can add to it the next time I come. What would you rather do?”

“I’ll fill it out,” replied Mae. “Should I put down the things we talked about today?”

“Yes, if you don’t mind,” answered Grace. “Then we won’t forget anything and you can add anything we didn’t get to.”

Grace visited Mae and Tisa at home two more times in the next two weeks. She noticed that the mobile home, while sparsely furnished, was always neat and there were always toys out for Tisa to play with. Outside was a small grassy area, a small plastic swimming pool filled with sand and some toys, and a toddler swing hanging from a sturdy tree branch. During her second visit, Grace reviewed the *Parent Handbook for the North Carolina Infant-Toddler Program* and the *Infant Toddler Child and Family Rights* document and answered Mae’s questions about them. They completed required forms that they had not completed at the previous visit. Mae continued to feel comfortable talking with Grace, and she especially enjoyed reviewing *Welcome to My World*. Grace asked some specific questions to learn more details about Tisa’s development and the routines of their day. Although Mae had felt hesitant to share personal information with a stranger before she met Grace, by this time she did not feel any of Grace’s questions were intrusive.

During these visits, Grace learned that Mae and James had known each other since they were teenagers. They were married a year after graduation from high school and live in the same town where they grew up. They have frequent contact with their old high school friends and with friends who are members of their church. Mae is more active in church than James is because he works most Saturdays and likes to sleep late on Sunday. Mae’s mother often stops by on Sunday morning to help her get Tisa ready for church, and James usually joins them for Sunday dinner at her house afterwards.

“Are there other children there that Tisa plays with?” Grace asked, as Mae was describing their Sunday routine.

“Yes, lots of cousins,” Mae replied.

“How does she do, playing with them?” Grace followed up.

“She really likes other kids,” Mae said with a smile. “It’s fun to see them together. The older ones make a fuss over her and carry her around, so she really likes them. She likes to watch my sister’s little boy, who’s just 8 months. He crawls around and she tries to follow him, but he’s faster than she is. She always cries when he cries.”

“Are there any kids her age, or preschoolers?” Grace continued.

“Yeah, a couple. She’ll play beside them, and she yells if they take her toy. I guess that’s pretty normal at this age.”

“Yes, she’s too young to understand sharing yet,” agreed Grace.

James’s mother also visits frequently. “She’s always got lots of advice,” noted Mae. “Like giving Tisa cod liver oil to fatten her up, or letting her cry it out at night. But she’s the one who keeps Tisa if I really want to go to Wal-Mart or to dinner with my girl friends. That keeps me sane.”

Grace also learned that the Richardsons were concerned about Tisa’s language development. “There are a lot of late talkers in our family, so it might be nothing,” Mae explained. “But it seems like most of her cousins were saying more words by now. We can pretty much tell what she wants, though.”

“Does she like books?” Grace wondered.

“Well, she’s pretty young for that yet,” Mae replied. “But she understands the words for some things, like bottle, or truck for James’s pickup. We know she knows those things because she looks in the right direction when we say them. Like we say ‘Here comes Nanna’ on Sunday morning and she looks at the door. And she’ll go get her Boo Bear if you tell her to. She listens a lot, and of course she looks at you when you say her name.”

The next big step was Tisa’s Entry Level Evaluation to determine whether she was eligible for the Infant-Toddler Program and to begin developing an IFSP. The evaluation was scheduled about three weeks after Grace’s first visit, when Tisa was about 14 months old. Grace spent a large part of her third visit talking with Mae about the evaluation. She explained that one purpose was to learn about how Tisa’s development compared to that of other children her age, and another purpose would be to determine whether she was eligible for the program. “Basically we play with her, watch what she does, and compare it to what other kids her age are usually doing. The evaluation is also based on what you tell us she does. A lot of times, she will do things with you that she won’t do with an unfamiliar person, so we pay a lot of attention to what you tell us.”

“I also want to make sure we are evaluating Tisa in the areas that are important to you,” Grace went on. “I know we’ve talked about this some, but can you tell me what you most want to know about Tisa right now?”

“Well, Dr. Sanders says she may be delayed,” Mae replied. “So I guess we just want to know how much. We need to know if her stiff legs are really a problem and if she’s going to have trouble learning to walk. Same with her talking – is it really a problem? Mainly we want to know what we need to do to help Tisa. I don’t know if you need to evaluate anything else about her weight and her eating. We know she’s skinny and she doesn’t eat, and we just need to know what to do about that.”

“You and Dr. Sanders have given us a lot of information already,” Grace agreed. “I think this evaluation will help us to know exactly where Tisa is in her development, and then we’ll know better how to help her.”

Mae wanted to know who would do the evaluation. “I’ll be there, of course,” said Grace. “You are part of the evaluation team, too. We might ask you to play with Tisa while we watch, or to explain things about her behavior. And I think, since you have concerns about how Tisa moves and how she talks, we should have John Adams, who is a physical therapist, and Carrie Smith, who is a speech-language pathologist, evaluate Tisa. How does that sound?”

Although Mae had felt hesitant about “more people coming into the house,” she and James agreed that Tisa would be more likely to act in her usual ways at home. James decided to take off work and attend the evaluation. “Sometimes she likes to go to me when she’s nervous about strangers,” he explained. “And I want to see what happens anyway.”

Although they had begun to trust Grace, James and Mae were anxious on the day of the evaluation. What would they find out? Were these therapists going to think they were bad parents if Tisa was behind? Would Tisa be scared or in a bad mood and not show them what she could do? They had scheduled the evaluation in the middle of the afternoon, when Tisa would usually be awake for a longer period of time, but you could never tell what she would do.

Their anxiety deepened because Tisa was still asleep on the couch when the team arrived for the evaluation. Grace reassured them that they could wait until Tisa woke up. “That will give you a chance to get to know Mr. Adams and Miss Smith a little,” she said, “and they can go ahead and ask you some questions about what you have seen Tisa do.”

After that, the evaluation went smoothly and the Richardsons felt more relaxed. There were a lot of questions, but they never felt rushed to answer. When Tisa woke up, she seemed startled by all of the people in the living room and hid her face against James for a few minutes, but curiosity about the new faces won out and she was soon ready to play. Grace played with Tisa first because Tisa already knew her. The Richardsons were happy to see that Grace let Tisa explore new toys first before trying to get her to do something specific. “She knows Tisa will just quit if you push her too hard,” James whispered to Mae. They were pleasantly surprised when Tisa followed directions to put Boo Bear in a basket (“I didn’t know she understood that!”) but also were surprised when she didn’t imitate Grace pretending to drink from a cup.

“We’ve seen her do that,” Mae commented.

“That’s good to know,” said Mr. Adams. “Sometimes kids won’t do things for us that they will do for their parents, so this helps us to get a better picture.”

Mr. Adam’s comments reassured the Richardsons further. They were also reassured to see Miss Smith asking Tisa to point to the things they had told Grace she knew the words for. Tisa didn’t point to anything, including a toy truck that Miss Smith had put on the table, but she looked toward the window when Miss Smith asked, “Where’s the truck, Tisa?”

“I think she’s thinking about Daddy’s pickup,” Grace commented.

Toward the end of the evaluation, Tisa began to whimper and wanted James to pick her up. “I think she’s about done,” he said. “She’s not going to do anything else you ask her to do without another nap.”

“That’s OK,” said Grace. “I think we have learned a lot about Tisa today.”

Grace helped the two therapists to gather up the assessment materials and stepped outside to speak with them before they left. After they left and Tisa had dropped off to sleep, Mae asked Grace, “Can you tell us anything yet? Is she really delayed?”

“Well, we need to see the whole report,” Grace answered. “But that’s why I stepped out to talk with Mr. Adams and Miss Smith. We all agree with Dr. Sanders that she has some delays, and she may qualify for the Infant-Toddler Program based on her established diagnosis or under the developmental delay category. I should be able to bring you the report in a few days. Shall we go ahead and schedule a time?”

Waiting for the report was another anxious time for the Richardsons, and the results came as a shock to Mae when Grace delivered them. Although Grace emphasized all of the things Tisa was able to do, the report said that in most areas her development was more like that of a child 7 to 9 months of age.

“This is awful!” Mae said. “I just can’t believe this. Will she ever catch up?”

Grace’s first reaction was to reassure Mae, but she also wanted to respond to the obvious shock and pain in Mae’s voice. “It’s a shock to get news like this, even though you were already concerned about Tisa,” she said kindly.

“It is a shock.” Mae agreed. “And I can’t help but think, what would have happened if we had started services right after she was born? Have we ruined her chances to have a normal life?”

“It sounds like you’re wondering what would have happened if you had started the program sooner,” Grace reflected.

“Yes,” said Mae. “But I guess there’s no point in wondering what if...? I mean, all we can do is start from where we are.”

“I think that’s right,” affirmed Grace. “Tisa has so much going for her. She likes to play and move around, she’s very determined, and she lets you know what she wants. She loves to be around people. She has you and James, and all of your family and friends behind her. I think her chances are really good. It won’t surprise me if she makes good progress pretty quickly when she starts the program.”

“If we can just get her eating and sleeping better,” added Mae. “That may be what’s been holding her back.”

“I know that will help,” Grace agreed. “It sounds like you’re ready to start thinking about the IFSP. That will give us a plan for helping Tisa.”